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ABSTRACT

This discussion of friendship in the lives of people with developmental disabilities raises questions which probe the nature of friendship, friendship between people with and without disabilities, and the special challenges involved in making and keeping friends. First, four dimensions of friendship are identified and discussed: (1) attraction (the "something" that draws friends to one another); (2) embodiment (the particular ways people physically enact friendship); (3) power (the extent and ways in which friends can make choices about their relationship); and (4) community (the social context of friendships). The frequency and quality of friendships between people with developmental disabilities are considered, as are the special problems of friendships between people with and without disabilities. Among problems mentioned in embodying friendships for people with developmental disabilities are the practical difficulties involved in going places easily and safely as well as the lack of personal funds. Personal challenges in extending the energy to make and keep friends are discussed, including a lack of confidence and maintenance of a protective shell. Issues of power, such as the negotiation of power differences, are also considered. Finally, friendship is considered as a way to human development and as a product of friends' conscious choice to situate themselves within a "community of resistance," which counters dominant social beliefs that devalue the community's members and their relationships and which contradicts the notion that friendship must be a purely private, exclusive, and one to one affair. (Contains 58 references.) (DB)

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Perspectives On Community Building

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Unlikely Alliances

Friendship & People with Developmental Disabilities

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perspectives

On Community Building

Reports in the Perspectives on Community Building series discuss issues of concern to those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life.

These papers are based on visits to innovative human service programs and focus group discussions. Program visits include intensive interviews with program leaders and staff, and usually with some of the people they serve. Discussions include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

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Contents

Four Dimensions of Friendship 3

The Question of Attraction 5

Are people with developmental disabilities able to attract people without disabilities? 5

Why do so many people with developmental disabilities lack friends? 7

Do people have friendships that are invisible to outsiders? 8

Do friendships matter to people with developmental disabilities? 10

Can relationships between people with and without disabilities be friendships? 12

The Challenges of Embodiment 15

Some external challenges 16

Some personal challenges 19

Issues of Power 21

Pushing backconstraints 22

Negotiating differences in power 24

Friendship as a way to human development 26

The Context of Community 28

Notes 31

References 31

Nature assigns the Sun—
That—is Astronomy—
Nature cannot enact a
Friend—
That—is Astrology.

–Emily Dickinson

Friendships can't be calculated by dispassionate observers, as the orbit of the sun can; but their meanings can be better understood by reflective participants, as other human mysteries can. Better understanding could make us better friends and wiser assistants to people for whom friendships are unlikely alliances because they are separated, and isolated, by prejudice against disability.

English language dictionaries mirror the ambiguity of friendship. In common usage, someone attached by feelings of affection is a friend, someone who acts as a patron or benefactor is a friend, and someone who is simply not hostile is a friend. This ambiguity helps to illuminate a dispute between a special education teacher and a mother who has successfully advocated for her son's inclusion in high school.[2] The young man's teacher points with pride to his many friends. The teacher notes that almost everybody in school knows the young man's name and says 'hi" to him, and that some of the young women in his class have befriended him, as evidenced by their willingness to look after him on a class trip. The young man's mother says that, though he is well known in school, other students don't treat him as an equal or spontaneously involve him in their lives outside of school. She believes that people are friendly but that he has no real friends to count on. She wants the people who assist her son to think more deeply about friendship and to work in a more focused way to support others to become his friends. She says that it worries and angers her that the teacher can't understand her concern.

This disagreement over the meaning of friendship contains the questions that concern us in this chapter. What can people with developmental disabilities expect from their social relationships, particularly their relationships with people without disabilities? Is the meaning of 'friend' exhausted by lack of hostility or by benevolent patronage? Or are some deeper meanings possible, and, if they are, how can we understand them, call them forth, and support them? What challenges come with friendship?

We think that these are difficult questions for three reasons, each of which offers a guide to the kind of discussion appropriate to the topic. First, modern patterns of practice and belief segregate and isolate people with developmental disabilities as a matter of course. Outside of families and human service settings, sustained relationships of any sort involving people with developmental disabilities are unlikely alliances. Instead of being able to consider many and varied experiences which extend over generations, we can only draw on a few experiences, most of which are measured in much less time than a decade. So our discussion must be tentative, a way to find the next steps in a long journey newly begun.

Second, a great deal is at stake. People with developmental disabilities have suffered terrible consequences from being seen as less than human (Wolfensberger, 1975). However fuzzy or implicit the common understanding of friendship may be, most people would say that someone incapable of friendship is diminished in a basic quality of humanity. Aware of this, and moved by their own love, a growing number of parents of people with developmental disabilities hope powerfully for true, sustaining, and lasting friendships for their son's and daughter's pleasure and protection. Jeff and Cindy Strully spoke for many other parents when they said, "It is friendship that will ultimately mean life or death for our daughter. It is her and our only hope for a desirable future and protection from victimization." (Strully & Strully, 1993) So our discussion must be careful never to compromise the human dignity of people with developmental disabilities and cautious not to betray hope with inflated stories of easy success or perfect relationships.

Third, friendship itself is problematic. Friendship has stimulated beautiful, wise, and whimsical thoughts about some of the highest and best human possibilities (see Welty & Sharp, 1991). And contemporary criticism exposes the elitist, individualistic, and patriarchal biases in the ways many thinkers have understood and shaped our society's written understanding of friendship (Heilbrun, 1988; McFague, 1987; Raymond, 1986). On some classical views, women could not be true friends, foreigners could not be true friends, people of low status could not be true friends. All of these groups lack the qualities of intellect and spirit and the social position assumed necessary for friendship (Benveniste, 1973; Easterling, 1989). On some modern views, friendship is aside and

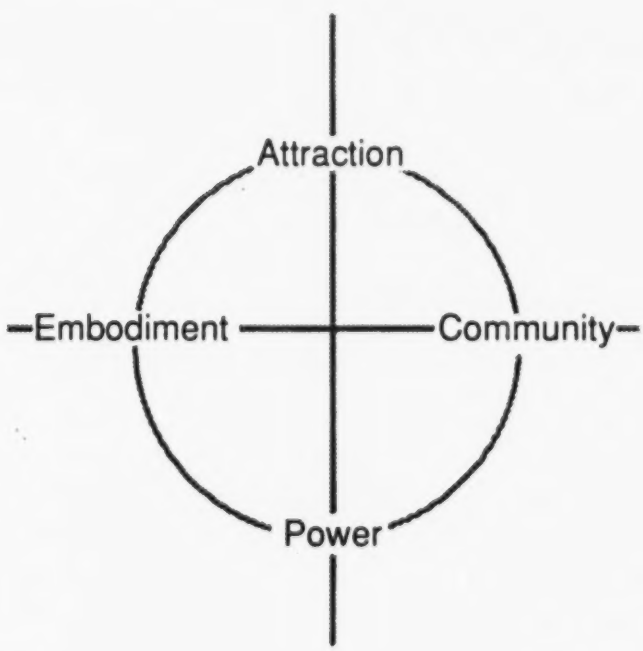
930312

apart from the real, fundamentally competitive business of life. It matters mostly to women and children and only to men as a brief respite from the daily fight for a living (Lasch, 1978; Traustadottir, 1992). So our discussion needs to be critical of assumptions about friendship.

Four Dimensions of Friendship

Mary Hunt's (1991) consideration of friendship provides a good starting place because she calls attention to important aspects of friendship that are easily ignored in a culture given to individualism. Instead of focusing solely on its advantages to isolated individuals, Hunt sets friendship in the context of building up a more just community. Friendship, she believes, forms the goal of human community and the defining image of ethical relationships. "Justice involves making friends, lots of friends, many kinds of friends... [who] empower one another to keep making change [in the structures and conditions that make friendship difficult or impossible]." (p.21) Hunt's reflections draw attention to four aspects of friendship; we have adapted them in order to explore friendships that involve people with severe disabilities.[3]

"Justice involves making friends, lots of friends, many kinds of friends...[who] empower one another to keep making change [in the structures and conditions that make friendship difficult or impossible]."



Attraction

- Attraction points to the mystery that brings friends together and recognizes that friends feel some kind of unity which they can preserve, deepen, and express by being together. Friends may say they feel attracted by their similarities or by their differences. However it is explained, whether it is ever stated explicitly or not, attraction refers to the "something", noticed or discovered, that draws friends to one another and keeps relationships alive.

Embodiment

- Embodiment identifies the particular ways people physically enact friendship, which differ from person to person and from relationship to relationship. People may embody a friendship by watching movies together, making music together, running a business together, exchanging the news of daily life, writing letters back and forth, meeting once a year to fish, or raising children together.

Power

- Power distinguishes the extent and the ways in which friends can make choices about their relationship for themselves as well as the accommodations friends make to the personal and structural constraints that affect their friendship.

Community

- Community recognizes that friendships are situated within, and contribute to, the life of a civic and social body. The choices that friends make either build up or break down a community that can offer its diverse members justice and belonging.

These four dimensions do not exhaustively define friendship; they simply identify important elements of its meaning. These dimensions of friendship matter particularly for people with developmental disabilities because the social construction of disability can make friendship particularly difficult for them. Community matters because people with developmental disabilities risk social devaluation –being seen as "not like the rest of us", even to the extent of being socially defined and treated as inhuman (Wolfensberger, 1991). Without the strength to resist, which is provided by a developing community, friendships cannot thrive. Power matters because disabled people typically have less of it than non-disabled people take for granted. Without action to deal with imposed inequality, friendships cannot thrive. Embodiment matters because people with developmental disabilities risk losing friends simply because they need assistance to undertake the activities that lead to and express friendship. Without effective assistance, friendships cannot thrive. Attraction matters

930312

because people with developmental disabilities have just as much capacity for friendship as any other people do. Because of the power of attraction, friendships can thrive.

The Question of Attraction

The question of attraction haunts many discussions about friendships for people with developmental disabilities. According to parents, there are at least three ways that others dismiss their concern for their children's friendships. Some people say that friendship is not a problem: people with developmental disabilities already have all the friends they need or want, especially among their "peers" –the other clients of congregate services. Some people say that friendship, as people without disabilities understand it, doesn't matter to people with developmental disabilities: people with developmental disabilities lack the capacity to understand it. Some people say that friendships, particularly friendships including people without disabilities, are an unrealistic dream: people with and without disabilities have too little in common to make friends. These three dismissals have a similar element. Each assumes that people with and without disabilities will not discover and pursue mutual attractions because of the way people with disabilities are.

"Who comes into a person's life may be the single greatest factor of influence to what that life becomes."

Are people with developmental disabilities able to attract people without disabilities?

Summarizing his discussion of human development, Robert Kegan observed,

> "Who comes into a person's life may be the single greatest factor of influence to what that life becomes. Who comes into a person's life is in part a matter of luck, in part a matter of one's power to recruit others, but in large part a matter of other people's ability to be recruited. People have as varying capacities to be recruited as they do to recruit others" (Kegan, 1982, p. 19).

Does disability necessarily lead to low capacity to recruit and be recruited? Can people with developmental disabilities recruit people without disabilities into their lives? Are people without disabilities recruitable by people with disabilities?

The experience of many families clearly answers, yes! People with developmental disabilities can powerfully recruit others into

"...labeling and exclusion of people with disabilities have become so taken-for-granted that instances of acceptance have been glossed over or ignored"

their lives and activate good relationships through which people work for social justice. Based on his study of six families, three of whom adopted their children with disabilities, Biklen (1992) concludes that the kinds of positive relationships that these families work to achieve within themselves should guide public policy and educational practice. Schools should support all children, unconditionally, to be full participants in every day life, as these six families strive to do. Professionals should recognize and assist people's natural desire to be fully involved in life, as these six families strive to do. Other people should make the chance to discover and enjoy people's individual gifts, as these six families strive to do. These families fully include and work to expand opportunities for their disabled member, not from a sense of pity or duty, but because their appreciation of his or her identity flows into a clear sense of what is right.

Dorothy Atkinson (1986) studied the relationship networks of the 28 women and 27 men discharged between 1971 and 1981 from the institutions serving one English county. She found that all but 7 people had involved at least one neighbor in social and helpful relationships. Almost three-fourths of the people had non-disabled acquaintances they see regularly, and about half the people had at least one supportive friend without a disability. She noted that these people without disabilities make a real and sustained contribution to the lives of people with developmental disabilities, offering information, advice, assistance, support, conversation, and company.

One reason that these positive images of relationship have not yet been influential in shaping policy and practice is that attention has focused elsewhere. During the past twenty-five years of service reform, concern for the rights of people with developmental disabilities overshadowed attention to their relationships.

As Steven Taylor and Robert Bogdan point out, many workers took up the sociology of deviance as an effective tool to explain, guide, and justify their reforms. This understanding of the negative effects of stigmatizing labels and practices fueled the fight for equal rights for people with developmental disabilities and led to much positive change, but "it has too often been interpreted in terms of the inevitability of rejection of people with obvious differences... labeling and exclusion of people with disabilities have

930312

become so taken-for-granted that instances of acceptance have been glossed over or ignored" (Taylor & Bogdan, 1989, p. 25).

To complement the understanding offered by a sociology of deviance, Bogdan and Taylor have begun to outline a sociology of acceptance, based on the recognition that some people with and without disabilities have formed long standing, close, and affectionate relationships which neither deny disability nor stigmatize a person on the basis of disability. In such relationships, people without disabilities see, enjoy, celebrate, and protect the positive qualities, the abilities, and the individuality of people whose disabilities loom very large to most people outside the relationship (see Bogdan & Taylor, 1987; Bogdan & Taylor, 1990 & Taylor & Bogdan, 1989).

Why do so many people with developmental disabilities lack friends?

If people with disabilities can recruit others into their lives, and if accepting relationships are possible, a reasonable person might mistakenly think that friendships will take care of themselves. Maybe people will have few friends among people without disabilities, but certainly they will have many good friends among people with developmental disabilities.

A survey of US residential programs asked knowledgeable staff about contacts between older clients of residential services and their friends (Anderson, Lakin, Hill, & Chen, 1992). The survey broadly defined a friend as a person other than a family member with whom the resident looks forward to spending time, either at the facility or somewhere else. Under this definition a friend might be another resident (and about 30% of the time, staff identified another resident as a person's closest friend) or it might be a non-disabled person (and about 14% of the time, staff identified a non-disabled person as the resident's friend) or it might be another disabled person. The survey estimates that about half of people with mental retardation over 63 years of age either have no friends at all or never see their friends. Only 25% of those people staff identified as having friends see a friend once a month or more. Compounding this group's isolation, about half have no contact at all with their families.

Unfortunately, this level of isolation does not appear to result just from the age of the people involved. In a larger survey, representative of the whole US population in residential programs for people with mental retardation, staff in close contact told inter-

viewers that about 42% of people in community programs and about 63% of people in institutions had no friends, even among other residents or staff (Hill, Rotegard, & Bruininks, 1984). This study defined a friend as anyone the resident liked and did things with on the resident's own time.

These findings call for action, and the researchers who report them have sensible recommendations to offer: prefer smaller residential settings over larger settings because the surveys show that smaller settings offer people more social contacts; increase people's involvement with neighbors (about two-thirds of whom were described by staff informants in the study of older residents as either "warm and accepting" or "friendly"); increase people's use of ordinary community places such as shops, churches, libraries, and parks; increase attention to peoples leisure time opportunities; and concentrate staff attention on building up people's social contacts. But these finding also deserve thoughtful, even meditative, consideration: why do so many people have no friends?

Do people have friendships that are invisible to outsiders?

Perhaps these findings say more about the difference between life as people with developmental disabilities live it and the lives that staff or other outsiders can see. Maybe there are many more friendships among people with developmental disabilities than are apparent to observers. Anne McDonald, who survived fifteen years in an institution for "profoundly mentally retarded children", describes friendships among inmates that were invisible not just to ordinary staff, but to her teacher, ally, and friend Rosemary Crossley as well. Some people that staff assumed incapable of communication were, it turns out, not babbling and shrieking but conversing. Once Anne could communicate with staff, however, she kept these relationships secret for two reasons: she feared that even Rosemary, her closest ally, would not believe that her friendships were real; and, she thought that if staff suspected that these friendships existed, staff would break them up in order to retain control of the ward (Crossley & McDonald, 1984). Poet Robert Williams (1989) expresses this disjunction of perception in "Dick and Jane," Dick and Jane are institutionalized lovers who have "shared the same mat since they were children" and who find pleasure in one another's touch:

...they move an inch or two closer to each
other
hoping that the staff doesn't pick up on
the subtleties
of the moment;
they don't of course. (p. 13)

Knowledge of the possibility of invisible friendships instills caution on two counts: people with authority to move people with developmental disabilities around will consider people's relationships when they make decisions about such movements (Berkson & Romer. 1981); and outsiders will be careful to remember the limitations of their point of view, keep open the possibility that much more is happening than they know, and inquire actively for different perspectives, especially the perspectives of the involved people with disabilities. However, the possibility of invisible friendships does not imply that all people in congregate residences and day programs have friends, and it does not engage the question of friendships between people with developmental disabilities and people without disabilities.

Indeed, if staff cannot even recognize some friendships among people with developmental disabilities, there could be such a gulf between the experiences of people with and without disabilities that friendship between them is unattainable. There is, however, a simpler explanation for this lack of staff awareness. The norms and beliefs that organize most service settings into distinct, unequal sub-cultures of keepers and inmates explain staff's blindness better than the argument that people with developmental disabilities are a kind of distinct sub-species does (Barnes, 1990; Glouberman, 1990). Concern for friendship means hard work to minimize the status and power differences between people with disabilities and the people who assist them. Only then will concerned people be able to better appreciate individual differences and more accurately describe the social worlds of people with disabilities.

Do friendships matter to people with developmental disabilities?

Of course, even within the closed environments of congregate services, staff do see friendships. Staff surveyed in the studies summarized above said that about half the people do have friendships: mostly with other residents. But they may not think they are seeing friendships like their own. Any possibility of friendship, even friendships among people with developmental disabilities themselves, has been in question within the lifetime of many adults now alive. A special education teacher in a segregated community program provided this explanation of why her moderately mentally retarded students had few social contacts: "They don't have friends because they don't have much in the way of a self concept. So they don't value the esteem of others" (Evans, 1983, p. 122). MacAndrew and Edgerton (1966) summarized a thorough and sensitive description of a ten year relationship with these words:

> We have outlined what we take to be the principal characteristics of a highly improbable, strikingly pervasive and intense friendship between two severely retarded young men. Hopefully, we have provided sufficient detail to convince the reader that this long enduring and highly elaborated relationship is indeed a *friendship* of a highly human order. The existence of such a relationship between two persons of such enfeebled intellect must be counted as compelling testimony to the essentially human character of even the most retarded among us.
> (p. 620, emphasis in original)

Even when they are recognized, friendships among people with developmental disabilities may be trivialized. Patrick Worth (1990), a leader in the People First movement, shared his experience in a group home and a sheltered workshop:

> Staff put down our friendships when they didn't try and break them up. They acted like our friends were less than their friends. It's like they were saying, "Isn't it nice that you have your little friends to play with." When a friend got sick and you asked to go to the hospital and see him, they acted like you were being foolish. When a friend got in trouble and had to go to a discipline meeting, they acted like you were from Mars when you said you wanted to go to

> the meeting with him. "It's none of your business," they said. "We have to protect confidentiality," they said. Like we didn't talk to our friends about the trouble they were in. Like we didn't owe our friends any help. And sometimes a friend got moved away without even having a chance for us to say good bye.

Seeing friendship through the lens of quantitative research can also have the effect of trivializing friendships. Defining a friend as a person "other than family or staff with whom the resident looks forward to spending time" (Anderson, Lakin, Hill, & Chen, 1992, p. 493) powerfully documents people's isolation –since only about 1 in five people have weekly contact with such friends– but it doesn't begin to touch common understandings of friendship. Lining up a corps of volunteers to provide individual recreation in facilities might give residents an activity to look forward to, but it would only provide them with friends in the most diluted sense of the term.

In a study based on coding the behavior of 208 people living in 18 group homes, based on observations at 15 minute intervals over a two day period, Landesman-Dwyer, Berkson, & Romer (1979) operationally defined friendship as "those pairs [of residents] who spent more than 10% of the observed time periods together" (p. 576). By this method, they discovered 16 "peer friendships." They conclude that "group home characteristics are better predictors of social behavior... than are individual variables.... For instance... in homes where the average intelligence is higher, residents are likely to spend more time in peer relationships" (578). This way of understanding friendship sets people who live in group homes apart both by the peculiar, diminished image of friendship it projects and prescribes for them and by its loud silence about the possibility of friendships between residents and people without disabilities: its definition even rules out residential staff as potential friends. The implications of the study are also of questionable utility. Manipulating the variables of group home design to increase the number of pairs of people who spend 10% of their time together might not increase the number of people with developmental disabilities who have others to share with and count on.

As others listen better to people with developmental disabilities, the gap between the worlds of people with and without disabili-

ties diminishes, and a common sense of friendship emerges. Consider the powerful ordinariness of this woman's description of friendship, taken from an anthology of writings and art work by British people with developmental disabilities.

> As I've got older, I've got few friends and lots of acquaintances. A friend is one who knows all about you and loves you just the same; A friend to me is someone really special. Even if we don't see each other for years we can pick up where we've left off. I've got one friend I've known for 34 years. (Atkinson & Williams, 1990, p. 78)

Can relationships between people with and without disabilities be friendships?

People with developmental disabilities share activities with people without disabilities, and people without disabilities establish accepting relationships with people with developmental disabilities, but some wonder about considering these relationships friendships. Assigned to identify the practical implications of Robert Perske's *Circles of friends* (1988), some of the participants in a staff training course expressed skepticism about whether the relationships Perske described were really friendships. They asked: What do the people involved really have in common? Can these be equal relationships? What do the people with developmental disabilities contribute? Do people with limited language understand the relationship?

These questions reflect some sensible criteria for defining friendship: common interests, equality, mutuality, and understanding. In her careful study of four friendships involving people with and without disabilities, Zana Lutfiyya (1989; 1990) makes two important points about these criteria. First, the meaning of any friendship is created by the ways in which its participants enact and talk about it. Commonalty, equality, mutuality, and comprehension are best understood from the perspective of the friends themselves, rather than according to the measurements of a detached observer. Second, according to the people in them, these criteria are satisfied in the relationships she studied.

> Despite the differences in opportunities and experiences, at least some people with disabilities have successfully formed friendships with non disabled people. Through studying established friendships, we learn that both parties possess a respect for the

930312

> other. The friends also experienced a mutuality in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship... (Lutfiyya, 1990, p. 74.)

Jeff and Cindy Strully have grappled with the meaning of friendship for people with limited verbal communication as they have worked hard to support friendships for their daughter Shawntell. They report (Strully & Strully, 1985; 1989; 1992) on her changing relationships from their perspective and from the perspective of the young women who are Shawntell's friends. Biklen (1992) provided a helpful metaphor for the construction of meaning in these relationships. He suggested that, when someone's verbal communication is very limited, concerned others can read the person's behavior and expressions, giving voice to them as if they were a text. Like the members of the families Biklen studied, Shawntell's friends read their shared activities and their reactions to one another as signifying friendship. Through time, Shawntell's responses to going out for dinner with them, taking holiday trips with them, going to concerts, sports events and parties with them, listening to music with them, hanging out at school and around the house with them, and driving around town with them, all mean that they are friends. They speak of sharing confidences with Shawntell. They can identify her preferences and interests, overlapping but distinct from their own. They speak of trusting her and of learning from her. They talk about keeping up with one another as their paths in life diverge. They identify themselves to others as friends.

It is worth considering the messages in these questions about whether people with and without developmental disabilities can enjoy common interests, equality, mutuality, and understanding. The questions themselves suggest a sense of disability and of friendship narrowed and flattened by limited experience. Shawntell and Joyce are two young women of similar age and socio-economic status who attended the same high school and choose to spend considerable time together. To wonder what they have in common, one would need to place very great weight indeed on the effect of developmental disability on a person's interests or on the way a person is perceived. To wonder about their

equality, one would need to assume that disability necessarily means inferiority. To wonder about what they exchange, or whether Shawntell comprehends the friendship, one would have to estimate that expressed verbal intelligence plays the defining role in friendship.

Notice the potential for self-fulfilling prophecy. Those who decide that disability overshadows anything people might discover in common, that disability equals inferiority, and that friendships are conducted primarily in spoken sentences will neither seek nor support relationships between people with and without disabilities. Those who decide to share some of their life with someone apparently different, as Shawntell's friends have done, can create a relationship that seems significant but unremarkable to them. When outsiders ask about the "special" nature of their friendship, they will say, as Shawntell's friends do, that they are "just friends; no big deal."

Estimating a low potential for friendship because of apparent differences between people reflects a narrow and flat appreciation of friendship and how it grows. As the dominant modern way of understanding relationships, individualism assumes that each party acts as a separated, closed entity exchanging units of advantage or enjoyment with the other. From this point of view, as long as the score balances out, the two parties can be said to have a friendship; if either scorekeeper predicts a low rate of return, no friendship can happen.

An understanding of friendship as dialogue offers a much richer medium for its growth. On this view, people become more deeply themselves, as individuals, only in relationship to a variety of different others. People learn who they are by discovering new modes of expressing themselves along with others. Relationship with somebody different can induct a person into new possibilities for self-expression (Booth, 1988, Chapter 8; Taylor, 1991). Socrates communicates this in the form as well as the content of the *Lysis* (Plato, 1979). He demonstrates a way to make a friend through a discussion about friendship in which he enlarges both his understanding of himself and his circle of friends. Creating a friendship between a person with and a person without a developmental disability opens new kinds of self-expression and new definitions of self for both people. Balance in relationships understood as dialogue is more like the balance between dancers than the bal-

ance on a bank statement.

Clearly, friendship should not be ignored or trivialized because of developmental disability and friendship need not be limited by disability. Among many others, Anne McDonald and her friends (Crossley & McDonald, 1984) show that people with disabilities can make friends even in the most restrictive settings, that people with and without disabilities can make friends, even in those same restricted circumstances, and that these friendships can last and grow even stronger as the people involved come out of segregation. Along with Shawntell Strully and her friends, they demonstrate that these diverse relationships can thrive despite obvious differences in personal history, embodied experiences, abilities, and status. However, even when concerned people are inspired by its possibilities, friendships between people with and without developmental disabilities remain uncommon. Why?

The Challenges of Embodiment

Friends enact their relationship; they do their friendship in ways distinctive of the interests they share. As one man with a developmental disability put it,

> "I have two fishing friends and we fish. I have four football friends and we watch games and bet. I have three talking friends and we have a drink and talk – sometimes we go out and sometimes we come over to somebody's house. One of my friends is all three: fishing, and football, and talking. I also have a gardening friend and we ask about our gardens and talk about how to grow things and give each other cuttings. I also have a friend that was my teacher a long time ago and I go visit her and remember about bygone days."

Each embodiment of this man's friendships takes time and other resources specific to the activity. He needs to get to where the fish are and have the tackle to catch them; he needs the plot to garden in and the seeds to plant; he needs the money to buy a round of drinks when his turn comes.

The social consequences of disability challenge the embodiment of relationships. Some challenges arise in the external world and some are part of people's personal experiences.

Some external challenges

Difficulty in getting places easily and safely challenges friendships. Most people with developmental disabilities are pedestrians in a society that expects automobiles. Fewer and fewer neighborhoods offer a rich and accessible social life within walking or rolling distance, and many residential facilities are physically isolated. Convenient, affordable public transportation remains uncommon. Always asking for rides, or being one of a group of passengers in the facility's van, are typical experiences.

Most people with developmental disabilities are poor, and many activities cost money. One woman noted that she watches television most nights "because the TV's paid for."

Many places people want to go together, including many people's homes, are either physically inaccessible or very inconvenient to use.

People's time may not be their own. For people who are full time clients of developmental disability services, getting together with friends raises issues of control. Requirements for active treatment and restrictions on movement and outside contact, driven by service provider concern for regulatory compliance and liability, often leave people literally without free time.

Many people with developmental disabilities who live with their families report that their parents don't allow them to go out, or prefer that they not go out, except with the family or to supervised disability activities.

Staff concern for the isolation of people with developmental disabilities can result in direct, practical assistance in trying new experiences, making acquaintances, and making friends (see Firth & Rapley, 1990; Richardson & Ritchie, 1989). This concern takes a different turn if friendship becomes the intended outcome of a rehabilitation process. Staff can decide that the road to friendship leads through correct performance on a professionally prescribed curriculum of social skills. A brochure describing one such program identifies 21 skills "selected to address the most common behavior problems exhibited by people with developmental disabilities", including "...having a calm body and voice, interrupting the right way, [and] accepting no as an answer...." These approaches set up artificial pre-requisites to friendship, based on an abstract analysis of assumed social deficiencies in people with developmental disabilities. This extension of staff control leaves many

930312

people waiting in vain for performance in role plays to result in real friends.

Lack of adequate help with mobility and communication inhibits the enactment of people's friendships. For example, facilitated communication is a method for assisting written communication by some people with autism and other physical problems in producing speech (Biklen, 1990). Facilitated communication has given some people whom others believed were asocial and incompetent the opportunity to communicate their interests and desires. With the physical assistance of a facilitator, Kim types,

> my friends and me
> at rye high school i have friends
> they like me for me
> it feels like some magic
> how come i can't be like all the girls.
> (Bevilacqua, 1992, p. 6)

People with developmental disabilities are often socially disembodied. Friendships emerge among a variety of social relationships, including being part of a family, having a life partner, being a neighbor, being part of a workplace, and being a member of community associations (Ordinary Life Group, 1988). The more of these ties and connections a person misses, the fewer opportunities and supports the person has to meet and make friends.

Current policies and program designs seldom offer people with developmental disabilities flexible personal assistance to pursue activities with acquaintances and friends. Even staff from an exemplary supported living program reported, with remorse, that they are unable to consistently find time to help people become better connected to their community.

Pervasive unfamiliarity with people with developmental disabilities can make many people without disabilities uneasy about initial contacts. Uncertainty about whether one will understand a person, and when and how to offer help can keep people at a distance (Williams, 1977). Men are often uncomfortable offering help, especially help with eating or using the toilet. This gendered reluctance can restrict people's friendships to women (Traustadottir, 1992). People without disabilities, perhaps especially young men, may fear that their own status will suffer by close association with people with developmental disabilities.

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Some thoughtful people with physical disabilities believe that friendships among people with different disabilities are easier, and in some political and cultural ways more desirable, than efforts to make friends with people without disabilities. They point to the continuing experience of being seen and treated by non-disabled people as somehow unfamiliar, unwelcome, and inferior as a strong reason for putting priority on friendships with other people with disabilities. As Judith Heumann writes,

> Disabled people's desire to be accepted by nondisabled people has been a cause of internal discrimination. I believe that we must first accept ourselves and then if nondisabled people don't accept us, so be it" (in press, p?).

She goes on to provide welcome criticism of the assumption that

> ...the most important thing for us would be to be with nondisabled people.... I am concerned about the continued discussion of the percentages of disabled people and the appropriate statistical balance of disabled and nondisabled people as opposed to a balance based on interests, social aspirations, and professional aspirations" (p. ?).

To the extent that people with and without disabilities come to feel that friendships between them are somehow incorrect, they will narrow their search for friends instead of widening it.

Accepting relationships are possible, but widespread, unthinking prejudice against people with developmental disabilities remains a fact of life. Some people act as though people with developmental disabilities were repulsive or dangerous and scorn or shun them. Some people act as though people with developmental disabilities were passive, pitiable creatures and intrusively try to be their helpers or saviors. Some people act as though people with developmental disabilities had no sense or will of their own and look for a trained staff person or a parent figure to talk to instead of relating directly to the person. As one man with a developmental disability put it:

> I think the hardest part is you gotta defend yourself.... You gotta fight a, a reputation. People decide they know everything they need to know about me before they meet me even. They never get close

930312

> enough to see if there is something inside they might like after all. (Melberg-Schwier, 1990, p. 161-162)

Some Personal Challenges

Making and keeping friends takes energy and willingness to extend oneself. People with developmental disabilities participating in a conference on friendship identified three negative, self-reinforcing patterns of personal effects of the external challenges to friendship described above. In the first pattern, a person lacks experience with other people, or has had bad experiences with reaching out to others, and so lacks confidence. Lack of confidence keeps the person in, engaged in passive pursuits like watching television. This keeps the person from gaining experience and, over time, further decreases confidence. This pattern gets worse when the person eats and drinks too much to deal with loneliness, and so decreases the amount of energy available for reaching out. Conference participants felt that repeated invitations and encouragement's from others would help a person break out of this pattern.

In the second pattern, a person feels hurt inside because the person has been hurt, rejected, or abandoned by someone important. For protection the person makes a shell to keep others away. It may be a prickly shell, so that if someone tries to come close the person will hurt them to try to make them go away. It may be a hard shell, so that someone who tries to come close will feel like the person doesn't care about them. A woman who responded strongly to the image of a shell said,

> I know my parents love me and only did what they thought was best. But they put me in the institution when I was only a very little girl. For a long, long time I cried and cried because I missed them so much. Then I stopped crying. I think about this, but I still have my prickly shell. Knowing about it doesn't make it go away."

This pattern gets worse when people get psychoactive drugs to control behavior which is unacceptable because staff and physicians understand its functions poorly, because, as one man said, "The right pills might help, I guess, But if you get the wrong pills, they take all the interest out of you." Conference participants felt that others would need to be ready to take time and forgive a person caught up in this pattern for trying to hurt them, and that

they would need to be unafraid and keep trying to make friends with the person anyway. They also thought it was important to tell the person when the person was hurting them and to realize that the person may not want to be too close.

Maureen Oswin (1992) echoes this pattern when she describes the all too common practice of denying people with developmental disabilities the opportunity and support to grieve important losses. She explains this deprivation by identifying a mistaken notion that people with developmental disabilities lack the resources to comprehend, cope with, and grow through their losses. She associates failure to support people in bereavement with chronic depression, physical complaints, and "unexplained" anger.

In the third pattern, a person feels safe and comfortable because of the familiarity of the relationships the person already has and the person fears the uncertainty of change. As one man said,

> My mother and dad and me are very close. Sometimes I'd like to go out more on my own, but they really need me at home for company. My home could be a safe base to go out from, but it's a nice safe place to stay in. And I'm not sure other people would be as nice." Conference participants felt that a person caught in this pattern should not be forgotten, but invited to share activities repeatedly, so that they know they have a choice.

This third pattern seems to be related to the decisions described by Robert Edgerton (1988, 1991) as he summed up his learning from more than 20 years of research with people developmentally disabilities who live in the community:

> Each person...realizes that it is sometimes, even often, necessary to seek help from others, and although these people may provide badly needed assistance, with that assistance may come unwanted advice, restrictions, or interference. When this happens, the person with mental retardation must decide, like the rest of us must, whether we need someone's help badly enough to surrender some of our autonomy. What is central in the lives of these older people is the search for well being, and that

930312

> search involves an ever shifting calculus that attempts to balance freedom of choice against the need for the help of others. (Edgerton, 1991, p. 273)

Aware of these personal barriers to enacting friendship, some people advocate individually focused counseling or training as the way to friendships. Aware of the negative effects of socially devaluing attitudes, others call for large scale public education as a pre-requisite to integration. Neither of these approaches seems preferable to vigorous effort alongside people with developmental disabilities to tear down those external barriers that are within reach. Many challenges to making friends result, directly or indirectly, from the negative effects of common practices by the staff and programs that people with developmental disabilities rely on for assistance. Work to reverse these practices makes the best investment in improving the chances for good relationships.

Some people with disabilities, and some people without disabilities, want and could benefit from counseling to sort out personal difficulties in making and keeping relationships. However, greater autonomy, more money, better transportation, flexible and available personal assistance, and more respect from those who provide assistance seem prerequisite to the effectiveness of counseling or skill training.

Widely held prejudices will only change slowly, with increasing personal contact between people with and without disabilities, and it is unlikely that prejudice will ever be eradicated. It makes more sense to offer people practical help to realize that prejudice co-exists with the potential for acceptance than it does to wait for implementation of grand plans to educate the public. People who act on this realization will encourage people with developmental disabilities to find and build up the many accepting relationships that are already potentially available.

Issues of Power

Power enters into friendships between people with and without developmental disabilities in two connected ways. First, friends have to deal with constraints imposed on their relationship by outsiders who control the circumstances of the person with a developmental disability. Second, friends have to negotiate power differences between themselves. Failure to respond effectively to either of these issues of power threatens the strength and endurance of the friendship.

Pushing Back Constraints

Many people with developmental disabilities live and spend the day in situations where others have power over them. Even when staff in direct contact treat people with respect, impersonal others –service administrators and policy makers– retain power over them. This imbalance of power, and the responses friends make to it, shapes their friendships.

Most residential settings manage friends' access to one another. This control is sometimes explicit, as when friends have to have their contacts approved by an interdisciplinary team, or when friends without disabilities are required to undergo some form of training as a condition of spending time with their friend, or when staff members are forbidden to invite a friend home for a meal because it would violate wage and hour regulations. Other times, control of access is less direct: people have no privacy; visits with friends are interrupted by program routines; messages get lost; activities that require some cooperation from program staff break down because someone didn't pass along the right permission slip or the van has been re-routed.

One of the greatest powers service settings exercise is the power of definition. Staff define who the person with a developmental disability is and what is good for him or her. They assert the authority to say how it really is for a client. Often this process of definition reflects a preoccupation with finding fault in the person. A staff member describes a person with a developmental disability to the person's friend as manipulative, and cautions the friend against being "sucked into" or "feeding" the person's dependency. A staff member nods knowingly when a friend makes a positive comment about a person with a developmental disability and says sagely, "I thought that too, when I first met her." A staff member discounts ideas about a positive future as "unrealistic" or "inappropriate for someone who functions at that level." A staff member passes along comments about syndromes and symptoms.

Even when service workers enthusiastically endorse a plan for change, the systems they work in often respond ineptly and painfully slowly. Months can pass between a victory in a planning meeting and the first hint of real change.

Friends have to decide how to respond to these expressions of power over the person with a disability. The person's continuing need for assistance makes this a complex problem. Some people with developmental disabilities fear offending the people they

rely on. Some people without disabilities doubt their own perceptions when they run counter to professional judgments.

Friends may decide to push back. Nicola is a 21 year old woman who attends a day program for people with developmental disabilities. A group of six of her friends, with whom she regularly shares a variety of social activities, reviewed her individual program plan together and wrote a letter to her IPP team which begins:

> It's Tuesday night and we're all together with Nic.
> In the pub. We have just read your report... with disbelief, we're not so sure that we are discussing the same person...
> We don't see Nic in the same light as you do, and we feel you need to see the Nic that we know, because otherwise we don't think Nic's best interests will be served...

They go on to make several concrete suggestions for assistance that they believe would be more relevant and better focus her strengths. The service system made no effective response to their comments.

The response from a threatened system can be much less benign. Working as a staff trainer in an institution, Rosemary Crossley discovered that several inmates were able to communicate, given assistance by someone who cares about what they have to say. Rosemary's discovery created close, increasingly personal relationships between her and several of the young people involved, including Anne McDonald, who ultimately came to live with Rosemary and her partner (Crossley & McDonald, 1984). Her personal engagement led her to challenge the constraints of the institution in a number of ways, including, spending her free time with Anne and other residents, taking Anne home for weekends and holidays, creating techniques and materials to support further communication, feeding Anne and other residents, working the bureaucratic system for a variety of resources, and, ultimately, helping Anne get a lawyer to free her from the institution. From very early in their relationship, these activities threatened the institutional system which reacted by invoking medical authority to publicly discredit Rosemary and her assertion that Anne and several other young people were able to think and communicate, demoting her, forbidding her to visit outside work

hours, transferring her, and separating the group of young people involved. Elks (1990) helpfully analyzes the situation by contrasting the approach of Rosemary, a personally involved ally, with the institution professional approach like this:

Dimension of Difference	***Personally Involved Ally***	***Institution Professionals***
Overriding concern	Quality of life	Efficiency of operation
Involvement	Personal, daily, all hours, hands on, informal	Professional consultation, formal, day appointments only
Assessment issues & standards of proof	Open to all, informal, commonsense, anecdotal, subjective	Professionals only, formal scientific, controlled, objective
Sources of support & power	Friends, media, courts, independent professionals	Bureaucratic & professional authority, legislation
Preferred way to make change	Personal & direct response to needs	"Normal [official] channels"
Gender	Female	Male
Status	Low	High
Conceptualization of controversy	Civil rights versus institutional denial & obstruction	Professional judgment versus irrational & emotional lay opinion

Negotiating Differences In Power

Power issues arise within any relationship. Questions between friends about how to make decisions, how to share resources and tasks, and how to deal with conflicts, which are common to all relationships are sharper in a friendship between a person with and a person without a developmental disability. This is because there is typically a power difference between the friends: one friend can come and go relatively freely and the other friend's time and movement may be under staff control; one friend may have more disposable income than the other; one friend may have transportation while the other does not; one friend may be seen by others as capable while the other is not; one friend may

930312

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feel confident about changing jobs or living places while the other is unable to.

The person with less power usually sees and feels this difference more clearly than the more powerful person does. People without disabilities take for granted many small everyday powers which are privileges in the world of the person with a disability.

When a person with a developmental disability needs regular physical or cognitive assistance from a friend, the friendship can be strained. One woman with a developmental disability said, "I liked my friend a lot, but I stopped calling her because she can't come to the group home because its so noisy and so I was always having to ask her for rides." This kind of resource sharing is easier to resolve, once people bring it up, than the issues that arise when a person with a developmental disability has limited experience of relationships or a limited repertoire of expression and treats his or her friend as if they were a staff person, or a parent, or a servant.

Sometimes the friend with a developmental disability has very, very few ties and connections to anyone other than the friend without a disability. This can leave the person who has a wider social network feeling like the person with a developmental disability wants more from the relationship than the person without a disability can give. This problem is exaggerated when the friends embody their relationship in a narrow range of activities. As one man with a developmental disability put it, "We love the same football team. So some parts of the year we see each other all the time. Other parts of the year, I miss him a lot."

People with disabilities may strongly and repeatedly test their friends because their personal history makes trust crucial to them. Anne McDonald risked her freedom, and jeopardized Rosemary Crossley's credibility, by refusing to cooperate with tests that would prove her ability to communicate to outsiders. As she explained in a conversation with Rosemary after refusing to respond compliantly to an investigating magistrate's questions,

> "Stubbornness is both my salvation and my besetting sin.... If surviving depended on any characteristic it was stubbornness: not letting the bastards grind you down" (Crossley & McDonald, 1984, p. 239).

Someone whose life experiences have not included living in an institution, or living with continual discrimination, may have difficulty comprehending these tests for what they are, opportunities to deepen and strengthen the friendship.

Finally, friends can fail in their efforts to deal with injustice or achieve the cooperation necessary from others to move toward a better future. Failure can bring hurt, uncertainty, and even resentment. Friends without a disability may wonder if they have done enough. Friends with a disability may even feel that somehow they have let their friends down.

Signals of real differences in power between friends can make dealing with these hurts and conflicts harder. Anthropologist Mary Catherine Bateson (1988) observed American's discomfort with relationships that do not seem to be symmetrical,

> ...the ethical impulse in American culture is toward symmetry.... Nothing in our tradition gives interdependency a value comparable to symmetry. It is difference that makes interdependency possible, but we have difficulty valuing it because of the speed at which we turn it into inequality. This means that all of the relationships in which two people complement each other –complete each other, as their differences move them toward a shared wholeness– man and woman, artist and physician, builder and dreamer– are suspected of unfairness unless they can be reshaped into symmetrical collegiality. But symmetrical relationships and exchanges alone are limiting... (pp. 104-105).

Real differences in power create the possibility that people with and without disabilities can transcend ordinary social patterns and develop a friendship which allows interdependence.

Friendship As a Way to Human Development

To sustain friendship through struggles with external constraints and internal contradictions, friends need a deeper way to understand friendship than many contemporary accounts offer. Friendship, especially friendship across a structural imbalance in power, requires endurance, discipline and courage. American society tends to understand friendship individualistically and therapeutically, as something done primarily for the improvement of individuals (Bellah, et al., 1985). On this view, friendships

930312

are not supposed to be a source of problems, but a means to pleasure and relief and personal betterment. Friendships are a private, individual matter, arising from the spontaneous feelings of the people involved. If the feelings turn bad, many people think the friendship is over. This may make one or both people sad, but nothing important to anyone besides the friends is lost. This way of understanding friendship offers little support for people who need to struggle with power issues in order to maintain their friendship.

Classical and medieval thinkers saw in friendship a way to maturity as a community member. Friendship imposes disciplines worth working to master, both for one's own sake and for the sake of one's community. In his lectures on friendship, Aristotle (1955) identifies friendship as the basis of effective government, as a foundation for practical knowledge of human affairs, and as a realization, a kind of harvest, of individual virtue: people become good in order to be worthy friends. He recognizes that "The wish for friendship develops rapidly, but friendship does not." (p. 264) and says that people must spend time together, over time, to develop knowledge and trust. He measures friendship in terms of the number of meals people eat together, allowing that friends will not know each other well until they have eaten a bushel-and-a-half of salt together.

Ailred, Abbot of Rievaulx in the mid-twelfth century, finds in friendship a way to strengthen a whole community, and a way to deepen spirituality by directly experiencing, through moments in the friendship, an image of the divine. Thus he sees friendship as worth working at and teaching about –once one has experience of friendship to draw on. He distinguishes childish friendship, which is based on calculation of mutual advantage or a fantasy of the friend's perfection, from mature friendship. Mature friendship begins when the friends live through disillusionment with one another. Ailred teaches that an extended period of what he calls "probation" is an essential stage of mature friendship. In this stage, friends test one another to try the other's trust. One result of this testing is that a friend can perform one of the central duties of friendship: giving criticism which upholds the ideals that the friends share in the context of mutual respect and affection. Ailred counsels that friendship should not be dissolved lightly, but only because of betrayal of the friendship itself.

930312

These ideas seem a bit odd to people accustomed to thinking about friendship in individualistic terms, but they provide a corrective for some of the negative effects of individualism on friendships. Ailred's idea is that older people in a community have a duty to instruct younger people in friendship first by example, but also by providing advice, encouragement, and teaching, and by insisting that the whole community work to achieve the civility necessary to support friends as they struggle. Aristotle's idea is that friendship isn't just a private matter between individuals, but that the positive effects of friends working to stay together for the long haul are a key resource to the whole community. Most of us don't live in a physically small world like the Athenian *polis* or the Cistercian monastery, and most of us wouldn't want to, but the men who formed these places have some important lessons for people trying to make friends today. If we think about what they have to say, we will remember. Friendship is not just spontaneous; it is intentional, involving duties and virtues that are worth working to develop. Friendship is not just for the self-improvement of individuals, it contributes to the good of a community.

The Context of Community

Friendships between people with and without disabilities are unlikely alliances, not because people are unable to attract and enjoy one another, but because of difficulties imposed on making and keeping relationships by the social construction of developmental disability. Dealing with the consequences of beliefs that justify the social exclusion and therapeutic control of people with developmental disabilities is far more than a two person job. To survive effectively in a fragmented society with little room for people with developmental disabilities, friends need to make a conscious choice to situate their friendship within a community of resistance.

A community of resistance is simply a group of people who, among other shared interests, recognize the negative effects of common beliefs and practices on their friendships and their friends, and support one another to get on with their lives. They contradict the notion that friendships must be purely private, exclusive, and only one to one (Hunt, 1991).

Judith Snow, Jack Pearpoint, and Marsha Forest sustain their

fourteen year friendship by reaching out to include people in their friendship (see Pearpoint, 1990). They purposely seek people who join them in celebrating diversity and thus counter the notion that there is something odd or saintly about them. They purposely seek people who will join them to fight the injustice of systems that divide and violate people. They purposely seek people they can have a good time with. Their friendships are not compartmentalized, and separated from the rest of their lives, but complex, and mixed-up with their whole lives. Each is friends with the other, and each has other friends, but their constellation of friendships is more than permutations of one-to-one relationships. The power of such a complex web of friendships can be considerable: it has sustained Judith's system of personal assistance against repeated bureaucratic attempts to standardize her out of existence; it has energized a large network of people committed to inclusive education; it has supported Jack and Marsha in their transition from ordinary job roles to the uncertainties of working freelance for social change; and, it has given them all a good deal of pleasure.

A community of resistance creates and gives life to a story that counters the dominant social beliefs that devalue the community's members and their relationships (Welch, 1990). This story relieves its members of the debilitating fear that there is something crazy or foolish about their friendship. As the lore grows about how its members have responded to challenges, the community's story guides and sustains action.

A community of resistance contains the hurts of its members, hurts that are too big for two individuals to hold between themselves alone. If it is to sustain real people, such a community cannot promise to fix its members or magically remove their pains with some technique. Indeed, Jean Vanier points out that community develops out of people's willingness to walk with one another in their shared weakness as well as their strength. "Community is the place where are revealed all the darkness and anger, jealousies and rivalry hidden in our hearts" (Vanier, 1992, p. 29). People don't need to be perfect to hold one another's hurts, they simply need to be willing to listen, to look for ways to act together when action makes sense, and to find ways to bear with each other when action doesn't help.

930312

In the context of a community of resistance, people will be able to deepen the attraction that draws them together, regardless of disability; they will be able to work against the barriers to embodying their friendships; and they will be able to struggle creatively with the power issues that arise around and between them. By so doing, they will contribute to a modest revolution, built of the daily activities of people who are unlikely allies against the beliefs and practices that make friendships difficult. As the community of resistance to separation of people with developmental disabilities grows, more people will be able to realize the promise of meeting the challenge posed by Robert Williams (1989, p.19), as he speaks on behalf of the people he has come to know in his work as an advocate with people in institutions.

* * *

Look deep,
deep into the hearts of
my people:

Witness their horror,
Witness their pain.

Horror and pain
your spoken words alone
will never soothe.

Do not try to explain it away,
they will never believe you...

Gallant and gaunt, their beauty.

Beauty,
your spoken words can never
capture.

Notes

1 This chapter arises from continuing conversations with our friends Kathy Bartholomew-Lorimer, Barbara Buswell, Marsha Forest, Gail Jacob, Zana Lutfiyya, Beth Mount, Frieda Neumann, Jack Pearpoint, Jack Pealer, Beth Schaffner, Judith Snow, Jeff and Cindy Strully, Steve Taylor, and Alan Tyne.

2 Examples which are not otherwise referenced are drawn from notes and recordings we made during five, one day long focus group meetings on the topic of friendship and people with developmental disabilities. Three of these meetings involved parents and friends of people with developmental disabilities and were convened by the Association for Community Living in Colorado in January and June, 1992 and by the Wisconsin Coalition for Advocacy in March 1990. One meeting involved people who use services for adults with developmental disabilities. This meeting was convened by INFO, a self advocacy group active in the Northwest of England, in November 1990. This meeting is also reported in Flynn, 1991. The fourth meeting, which involved adult service providers and some of the people they support, was convened by the Ohio Society for Autistic Citizens in May, 1985. This meeting is also reported in Pealer & O'Brien, 1985.

3 Hunt invites her readers to use her approach to stimulate conversation about friendships which will lead to new models (p.100). We have accepted her invitation, maintained the overall structure of her model, and modified its terms to better fit our own reflections on friendships involving people with severe disabilities. Moving counter-clockwise around the diagram, Hunt identifies the four poles of the diagram below as "love", "embodiment", "power", and "spirituality" (p.99). The words we have chosen retain the sense of Hunt's discussion.

References

Ailred of Rievaulx (1942). *Christian friendship.* (H. Talbot, Trans.). London: The Catholic Book Club.

Anderson, J., Lakin, KC, Hill, BK, & Chen, T. (1992). Social Integration of older persons with mental retardation in residential facilities. *American Journal on Mental Retardation*, 96 (5), 488-501.

Aristotle (1955). The ethics of Aristotle: The Nicomachean ethics, Books 8-9. (J. Thomson & H. Tredennick., Trans.) London: Penguin Books.

Atkinson, D. (1986). Engaging competent others: A study of the support networks of people with mental handicap. *British Journal of Social Work, 16, Supplement,* 83-101.

Atkinson, D. & Williams, F., (Eds.)(1990). *Know me as I am: An anthology of prose, poetry and art by people with learning difficulties.* London: Hodder & Stoughton.

Barnes, C. (1990). *'Cabbage syndrome': The social construction of dependence.* London: Falmer.

Bateson. M.C. (1988). *Composing a life.* NY: Atlantic Monthly Press.

Bellah, R., Madsen, R., Sullivan, W., Swidler, A. & Tipton, S. (1985). *Habits of the heart: Individualism and commitment in American life.* Berkeley, CA: University of California Press.

Bevilacqua, C. (May, 1992). Poetry by students using facilitated communication. *TASH Newsletter, 16,* 5, p. 6.

Berkson, G. & Romer, D. (1981). A letter to a developmental disabilities administrator. In R. Bruininks, C. E. Meyers, B. Sigford, & K.C. Lakin, (Eds.)*Deinstitutionalization and community adjustment of mentally retarded people.* AAMR Monograph Number 4. Washington, DC: AAMR.

Benviniste, E. (1973). *Indo-European Language and Society.* Coral Gabels, FL: University of Florida Press.

Biklen, D. (1992). *Schooling without labels: Parents, educators, and inclusive education.* Philadelphis, PA: Temple University Press.

Bogdan, R. & Taylor, S. (1987). Toward a sociology of acceptance: The other side of the study of deviance. *Social Policy, 18,* 34-39.

Bogdan, R. & Taylor, S. (1989). Relationships with severely disabled people: The social construction of humanness. *Social Problems, 36* (2), 135-148.

930312

Booth, W. (1988). *The company we keep: An ethics of fiction.* Berkeley, CA: University of California Press.

Crossley, R. & McDonald, A. (1984). *Annie's coming out (revised edition).* Ringwood, Victoria: Penguin Books Australia.

Easterling, P. (1989). Friendship and the Greeks. In R. Porter & S. Tomaselli (Eds.), *The dialectics of friendship.* New York: Routledge.

Edgerton, R. (1988). Aging in the community: A matter of choice. *American Journal on Mental Retardation, 92,* 4, 331-335.

Edgerton, R. (1991). Conclusion. In R. Edgerton & M. Gaston, (Eds.)"I've seen it all!" Lives of older persons with mental retardation in the community. Baltimore, MD: Paul Brookes Publishing Co.

Elks, M. (1990). Lessons from Annie's Coming Out. *National Council on Intellectual Disability: Interaction 4,* 1, 7-17.

Evans, D. (1983). *The lives of mentally retarded people.* Boulder, CO: Westview.

Firth, H. & Rapley, M. (1990). *From acquaintance to friendship: Issues for people with learning disabilities.* Kidderminster, Worcs.: British Institute of Mental Handicap Publications.

Flynn, M. (1991). *Moving On 2: Report from a conference of service users exploring friendship.* London: National Development Team for People with Learning Difficulties.

Glouberman, S. (1990). *Keepers: Inside stories from total institutions.* London: King Edward's Hospital Fund for London.

Heilbrun, C. (1988). *Writing a woman's life.* New York: W.W. Norton.

Heumann, J. (in press). A disabled woman's reflections: Myths and realities of integration. In J. Racino, P. Walker, S. O'Connor, & S. Taylor, (Eds.) *Housing, support, and community: Choices and strategies for adults with disabilities.* Baltimore, MD: Paul Brookes Publishing Co.

Hill, B., Rotegard, L., & Bruininks, R. (1984) Quality of life of mentally retarded people in residential care. *Social Work, 29,* 275-281.

Hunt, M.E. (1991). *Fierce tenderness: A feminist theology of friendship.* New York: Crossroad.

Kegan, R. (1982). *The evolving self: Problem and process in human development.* Cambridge, MA: Harvard University Press.

Landesman-Dwyer, S., Berkson, G., & Romer, D. (1979). Affiliation and friendship of mentally retarded residents in group homes. *American Journal of Mental Deficiency, 83,* 6, 571-580.

Lasch, C. (1978). *The culture of narcissism.* New York: Norton.

Lutfiyya, Z. (1989). *The phenomenology of relationships between typical and disabled people.* Doctoral dissertation, Syracuse University, Syracuse, NY.

Lutfiyya, Z. (1990). *Affectionate bonds: What we can learn by listening to friends.* Syracuse, NY: Center on Human Policy, Syracuse University.

MacAndrew, C. & Edgerton, R. (1966). On the possibility of friendship. *American Journal of Mental Deficiency, 70,* 612-621.

McFague, S. (1987). *Models of God: Theology for an ecological, nuclear age.* Philadelphia: Fortress Press.

Melberg-Schwier, K. (1990). *Speakeasy: People with mental handicaps talk about their lives in institutions and in the community.* Austin, TX: Pro-Ed.

Ordinary Life Group (1988). *Ties and connections: An ordinary community life for people with learning difficulties.* London: Kings Fund Centre.

Oswin, M. (1991). *Am I allowed to cry? A study of bereavement amongst people who have learning difficulties.* London: Souvenir Press (Educational & Academic).

Pealer, J. & O'Brien, J. (1985). *Personal relationships for people with developmental disabilities.* Proceedings of a Conference on Informal Support. Columbus, OH: Ohio Society for Autistic Citizens.

Pearpoint, J. (1990). *From behind the piano: The building of Judith Snow's unique circle of friends.* Toronto: Inclusion Press.

Perske, R. (1988). *Circles of friends: People with disabilities and their friends enrich the lives of one another.* Nashville, TN: Abingdon Press.

Plato (1979). The *Lysis.* In D. Bolotin, *Plato's dialogue on friendship: An interpretation of the Lysis with a*

new translation. Ithaca, NY: Cornell University Press.

Raymond, J. (1986). *A passion for friends: Toward a philosophy of female affection*. Boston: Beacon Press.

Richardson, A. & Ritchie, J. (1989) *Developing friendships: Enabling people with learning difficulties to make and maintain friends*. London: Policy Studies Institute.

Strully, J. & Strully, C. Friendship and our children. *JASH, 10*, 4, 224-227.

Strully, J. & Strully, C. (1989). Friendships as an educational goal. In W. Stainback, S. Stainback. & M. Forest (Eds.), *Integrating regular and special education students*. Baltimore, MD: Paul Brookes Publishing Co.

Strully, J. & Strully, C. (1993). That which binds us: Friendships as a safe harbor in a storm. In A. Novak Amado, Ed., *Friends: Connections between persons with and without disabilities*. Baltimore, MD: Paul Brookes Publishing Co.

Taylor, C. (1991). T*he malaise of modernity*. (CBC Massey lecture series, 1991). Concord, ON: Anansi Press.

Taylor, S. & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: Towards and understanding of acceptance. *Disability, Handicap & Society*, 4, 1, 21-36.

Traustadottir, R. (1992). The gendered context of friendships. In A. Novak Amado, editor. *Friends: Connections between persons with and without disabilities*. Baltimore, MD: Paul Brookes Publishing Co.

Vanier, J. (1992). *From Brokenness to Community*. The Wit Lectures, Harvard Divinity School. New York: Paulist Press.

Welch, S. (1990). *A feminist ethic of risk*. Minneapolis, MN: Augsberg Fortress Press.

Welty, E. & Sharp, R. (1991). *The Norton book of friendship*. New York: W.W. Norton.

Williams, P. (1977). *Our mutual handicap*. London: Campaign for the Mentally Handicapped.

Williams, R. (1989). *In a struggling voice*. Seattle, WA:TASH.

Wolfensberger, W. (1975). *The origin and nature of our institutional models*. Syracuse, NY: Human Policy Press.

Wolfensberger, W. (1991). *A brief introduction to social role valorization as a high-order concept for structuring human services*. Syracuse, NY: Training Institute for Human Service Planning (Syracuse University).

Worth, P. (1990, July). Presentation to The Summer Institute on Inclusive Education, McGill University Faculty of Education, Montreal, PQ.